

**Department of Health and Human Services
National Institute of Environmental Health Sciences
National Cancer Institute**

**Minutes of the Research Translation, Dissemination, and Policy Implications
Subcommittee of the Interagency Breast Cancer and Environmental Research
Coordinating Committee**

March 18, 2011

The Research Translation, Dissemination, and Policy Implications (RTDPI) Subcommittee of the Interagency Breast Cancer and Environmental Research Coordinating Committee (IBCERCC) was convened for a meeting on March 18, 2011 at 1:00 p.m. via conference call. The Chair of the subcommittee was Jeanne Rizzo, PhD of the Breast Cancer Fund.

Subcommittee Members Present

Beverly Canin
Ronda Henry-Tillman, MD
Karen Miller
Marcus Plescia, MD, MPH
Jeanne Rizzo, RN
Shelia Zahm, ScD

IBCERCC Members Present

Michele Forman, PhD

NIH Staff Present

Christie Kaefer, MBA, RD (NCI)
Jennifer Collins, MR (NIEHS)

I. BACKGROUND

The Interagency Breast Cancer and Environmental Research Coordinating Committee (IBCERCC) is a congressionally mandated body established by the National Institute of Environmental Health Sciences (NIEHS), in collaboration with the National Cancer Institute (NCI). This Committee is comprised of 19 voting members, including representatives of Federal agencies; non-federal scientists, physicians, and other health professionals from clinical, basic, and public health sciences; and advocates for individuals with breast cancer.

The Committee's primary mission is to facilitate the efficient and effective exchange of information on breast cancer research activities among the member agencies, and to advise the NIH and other Federal agencies in the solicitation of proposals for collaborative, multidisciplinary research, including proposals to further evaluate environmental and genomic factors that may be related to the etiology of breast cancer. The Committee serves as a forum and assists in increasing public understanding of the member agencies' activities, programs, policies, and research, and in bringing important matters of interest forward for discussion.

The objectives of the RTDPI Subcommittee of the IBCERCC are integrated and dependent on the objectives and activities of the other Subcommittees of the IBCERCC and include the following: to identify successful models as well as gaps in research translation and dissemination, to make recommendations to improve both with an emphasis on breast cancer and the environment; to make policy recommendations to that end; to address areas in which the scientific evidence on breast cancer and the environment supports precautionary public health policy; and to identify methods to expand public participation in the research translation and dissemination processes to more effectively involve patient advocacy and community organizations, environmental health, environmental justice as well as practitioners in public health and health care delivery.

The second meeting (conference call) of the RTDPI Subcommittee took place on March 18, 2011. During this meeting, Alice Chang's resignation was discussed, along with the need to generate nominations to fill the vacancy on the IBCERCC and RDTPI Subcommittee. The minutes from the February meeting were reviewed and the initial work teams were developed.

II. DISCUSSION

Nominations for New IBCERCC and RDTPI Subcommittee Member

Alice Chang resigned from the IBCERCC for personal reasons and nominations of individuals who can represent individuals with breast cancer are needed. The vetting process was discussed. After the nominations are submitted, the full slate will need to be reviewed again by Dr. Birnbaum for balance. Nominees must represent individuals with breast cancer and cannot be a Federal government employee. Jennifer suggested that Subcommittee members nominate as many individuals as possible and reminded the members that nomination letters should clearly explain how the nominees represent individuals with breast cancer. At the present time, the current Subcommittee members are fairly balanced in terms of the geographic regions they represent, so nominations of individuals from any region of the U.S. would be considered.

The full list of advocates originally nominated for the IBCERCC membership was requested. Subcommittee members discussed the names of some potential nominees:

- Charlotte Brody (Jeanne to confirm whether Charlotte is willing to be nominated)
- Julia Brody may be able to recommend some potential nominees from the Silent Spring Institute or the Massachusetts Breast Cancer Coalition
- Ysabel Duran , Latinas Contra Cancer
- Mhel Kavannah-Lynch, Executive Director, California Breast Cancer Program may be able to recommend some potential nominees, such as the advocate co-PI of Nail Salon Collaborative
- Pam Miller, works with Native Americans in Alaska (Karen Miller to follow-up)

Minutes

Jeanne suggested that RDTPI members review the minutes from the other two IBCERCC Subcommittees, as their work may inform the work of the RTDPI Subcommittee. Michele provided an overview of the State-of-the-Science Subcommittee's progress and Jennifer summarized the work to date of the Research Process Subcommittee.

The minutes from the February RDTPI meeting were reviewed and the action items from that meeting were discussed. Not everyone has been able to access SharePoint yet, so those that have not were encouraged to do so following the call. Some IBCERCC members have tried to access the site, but are unable to access the information, so important documents need to be sent by email until the access issues are resolved. NIH staff will send a SharePoint Users Guide to all IBCERCC members to increase everyone's familiarity with the site navigation and features available, such as how to create alerts for notification when new documents are added to the SharePoint.

The proposed goals for the RDTPI Subcommittee were also reviewed. Beverly suggested that health literacy should be incorporated into the Subcommittee's work and the group agreed it would be a valuable addition.

Jennifer asked if the RDTPI had defined the term "dissemination." The members discussed a broad definition that included the sharing of scientific findings with government, industry, public health practitioners, clinicians, and individual members of the public to influence personal choice.

Subcommittee Work Teams

Based on the proposed Subcommittee goals discussed in February, the RDTPI members decided to break into two work teams to draft an outline for review during the next Subcommittee meeting related to the following:

- 1) Beverly, Karen, and Ronda – Goal #1, Identify successful models and gaps in research translation and dissemination. This outline might be informed by a review of the following

- Patient advocacy
- Role of health care providers
- Community-based participatory research
- Examples of successful models could include the Breast Cancer Fund and the California Breast Cancer Program (CBCP), which has Requests for Proposals (RFPs) that require community involvement. Other models to consider include the NBCC.

Note: During group discussion, RDTPI members thought that Goals #2 (Make recommendations to improve research translation and dissemination with emphasis on breast cancer and environment.) and #3 (Make policy recommendations to address research translation and dissemination.) were closely related to Goal #1 and might be addressed by this same group once an outline has been developed for the first goal.

- 2) Marcus, Shelia, and Jeanne – Goal #4, Make recommendations for precautionary public health policy supported by scientific evidence. Policy recommendations might be informed by the following
 - Review recommendations made by the President's Cancer Panel (PCP) and National Conversation on Chemical Exposures (if report has been finalized)
 - Review other published reports by WHO, IARC, EPA, and NIEHS.

- Comparing differences between an evidence-based precautionary approach and risk assessment and hazard assessment approaches. Shelia suggested some articles by David Kriebel may be useful to review and will share with Working Group members. Other examples of approaches used by organizations to provide information about risk and uncertainty should be reviewed, such as the color coding approach used by Healthy Children, Healthy Families.

The RDTPI members felt that Goals #5 (Identify methods to expand public participation in research translation and dissemination processes) and #6 (Identify methods to more effectively engage patient advocacy, community organizations, environmental health, environmental justice advocates and practitioners in public health and health care delivery) dealt more with various aspects of communication and effectively reaching audiences. An outline for Goals #5 and #6 will not be developed for the next conference call, but all were asked to start thinking about these topics.

- Marcus asked if other individuals with expertise in health communication and dissemination research could be invited to join the RDTPI Subcommittee, or at least be invited to present to the group. Suggestions included Brad Hesse at NCI, Liam O’Fallon at NIEHS, Galen Cole at CDC, and experts from academic institutions. Marcus indicated Galen may be specifically able to assist with recommendations related to social media.
- There was discussion that the IBCERCC and RDTPI Subcommittee membership has sufficient representation of breast cancer advocacy organizations, but might benefit from additional expertise brought by representation of an environmental advocacy organization. Jeanne and others mentioned several coalitions with expertise in this area (all have published reports), such as the Campaign for Safer Cosmetics, Safer Families, Safer States, Women’s Health and Environment Initiative, Commonweal’s Collaborative on Health and the Environment, Coming Clean Coalition, etc.
- Karen and Jeanne both have lists of advocacy organizations that assist with dissemination, and a recommendation was made to ask Laura Nikolaides (IBCERCC member from NBCC) whether NBCC has a list of members they would be willing to share with the RDTPI Subcommittee. Additional listservs mentioned previously include the NIEHS listserv and a community-based participatory research listserv Ronda was familiar with.
- Beverly’s plain language information could also be included into the future outline developed to address these goals.
- Shelia will seek relevant communications information from Jennifer Loukissas, Communications Manager, Division of Cancer Epidemiology and Genetics, NCI, especially related to NCI’s activities with social media (e.g. Facebook, Twitter, YouTube) and partners for leveraging messages related to breast cancer and the environment.
- Jeanne and Ronda can also provide some information about relevant social media activities their organizations are involved with. Of particular interest is what has worked well and with which audiences? Examples mentioned were “mommy blogs” such as MomsRising.org.

Action Items:

- Nominations for IBCERCC/RDTPI Subcommittee:
 - RDTPI Subcommittee members will identify potential nominees who represent individuals with breast cancer, inquire whether they are interested in potentially joining the IBCERCC and RDTPI Subcommittee, and if so, submit nominations to Jennifer as soon as possible.
- Review minutes from other IBCERCC Subcommittees.
- SharePoint:
 - NIH staff to send the SharePoint User Guide to all IBCERCC members.
 - Subcommittee members need to try to access the SharePoint, if they have not already tried to do so, to review the materials and links available on the site.
- Resources:
 - Jennifer to check the FACA rules to clarify whether individuals with specific expertise in health communication and dissemination could be invited to join the Subcommittee or one of its Working Groups.
 - Christie to send list of risk communications experts compiled for a Breast Cancer and the Environment Research Program Key Message Development and Dissemination contract.
- Work teams:
 - Draft and circulate outlines for Goals #1 and #4 by April 8th (one week prior to next RDTPI Subcommittee conference call on April 15th).
 - Gather relevant information to assist with future work on Goals #5-6 (lists of advocacy organizations/coalitions that are dissemination channels).

III. ADJOURNMENT

The meeting adjourned at 3:45 p.m. on March 18, 2011.

CERTIFICATION

/Jeanne Rizzo/

Jeanne Rizzo, RN

Chairperson

Research Translation, Dissemination, and Policy Implications Subcommittee

Interagency Breast Cancer & Environmental Research Coordinating Committee

/Gwen W. Collman/

Gwen W. Collman, PhD

Executive Secretary

Research Process Subcommittee

Interagency Breast Cancer & Environmental Research Coordinating Committee

Proper signatures

Treat as signed, § 1.4(d)(2)